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CASE REPORT

The prevalence of epilepsy in the Zay Society, Ethiopia—An area of high prevalence

Shitaye Almu [a], **Zerihun Tadesse** [b], **Paul Cooper** [c], **Richard Hackett** [d,*]

[a] *Gondar College of Medical Sciences, Gondar, Ethiopia*
[b] *Addis Ababa University, Addis Ababa, Ethiopia*
[c] *Department of Neurology, Hope Hospital, Salford, United Kingdom*
[d] *The David Lewis Centre, Mill Lane, Warford, Alderley Edge, Cheshire SK9 7UD, United Kingdom*

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Summary Very high prevalence rates of epilepsy have been found in some developing countries. The Zay Society of Ethiopia was screened for epilepsy during a door-to-door survey and after neurological assessment, a prevalence of 29.5/1000 was found. Almost all the cases had primary generalised epilepsy in contrast to the predominance of partial epilepsy found elsewhere. Due to its historical isolation, epilepsy genes may have become widely disseminated throughout the Zay Society, accounting for the elevated prevalence.
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Introduction

Epilepsy is of worldwide public health importance because it is common, often accompanied by physical and cognitive disability and is widely stigmatised. Areas of high prevalence provide particular opportunities to study aetiological risk factors. The objective of the present study was to examine the prevalence and possible causes of epilepsy in an isolated community in Ethiopia where high rates of epilepsy had been anecdotally reported.

Method

The Zay Society lives on the shore and three islands of Lake Zeway in the Ethiopian Rift Valley, 160 km. south of Addis Ababa. This community of approximately 1000 people is endogamous and its language and culture are unique within Ethiopia. The economy depends on fishing and subsistence farming. Only two primary schools and a single primary care health centre serve the community.

As part of a public health improvement programme, every resident was visited by trained enumerators to gather demographic and social information using a questionnaire that included the epilepsy items from a WHO screening instrument for neurological disorders previously used in Ethiopia.[1] Before starting data collection, the screening

* Corresponding author. Tel.: +44 1565 640000; fax: +44 1565 640100.
E-mail address: dickhackett@doctors.org.uk (R. Hackett).

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questionnaire was translated into Zayigna, the language of the community, by local doctors familiar with the local culture and language and experienced in epilepsy, to ensure adequate symptom identification. It was then piloted in two Zay villages to ensure it was understandable and acceptable to the local population. Every subject who responded positively to any of the epilepsy items on the screening questionnaire underwent detailed evaluation by a doctor experienced in epilepsy. The diagnosis was established clinically. Active epilepsy was defined as having two or more unprovoked seizures, with at least one in the last 5 years, or the use of anti-epilepsy medication during that period. Seizure classification was based on the criteria of the International League Against Epilepsy,[2] though owing to the remoteness of the community EEG recording was impractical so this aspect of the criteria could not be applied, making classification essentially clinical.

The findings were analysed using the Statistical Package for the Social Sciences, version 10.0.

Results

Screening data were obtained from 1154 individuals of whom 82 were positive for epilepsy. Detailed neurological assessment identified 43 subjects with a history of seizures (Table 1). The subjects conforming to the definition of active epilepsy were 34, the prevalence rate being 29.5 per 1000.

Of those with active epilepsy, 28 (82%) had primary generalised tonic-clonic seizures, two had generalised tonic seizures, two secondary generalised partial seizures, one had complex partial seizures and one had myoclonic seizures. Only one subject with active epilepsy reported experiencing an aura, which was followed by focal jerking of a limb and automatism. Mean (S.D.) age of cases of active epilepsy was 19.0 (12.7) years. Eighteen (53%) cases were male. Mean (S.D.) age at onset was 9.6 (6.6) years with 82% of subjects having had the onset by the age of 15. Mean (S.D.) duration of epilepsy was 9.3 (8.8) years. Of the 34 cases of active epilepsy, 33 had had a seizure in the past 1 year and 25 (73%) had had one or more seizures in the month prior to the study.

During screening 41 (4%) of subjects who had no history of seizure disorder had a family history of epilepsy in a first or second degree relative. Every (100%) subject with active epilepsy or epilepsy in remission ($n = 39$) had a family history (Fisher's exact test $p < .0001$). One case had a history of developmental delay and one gave a history of head injury. No cases of active epilepsy had a history of perinatal complications, febrile seizures or CNS infection.

Fifteen (44%) of the cases of active epilepsy were receiving no treatment, 13 (38%) were on anticonvulsants, mostly phenobarbitone, three used traditional medicines such as herbal smoke, holy water or an amulet and three combined traditional and western medicines.

The educational level and occupation of the head of household did not differ between patients with active epilepsy and non-epileptic subjects. There was a significant clustering of epilepsy in certain villages. In Tulugudo, 5 out of 105 (5%) had active epilepsy as did 7 out of 64 subjects (11%) in Woldiya and 1 out of 14 in Gelila, compared to 0—4% in the other seven villages (Chi-square 20.6, $p = .014$).

Discussion

Though well-designed studies of epilepsy in Ethiopia,[1] Kashmir[3] and South India[4] have reported prevalence rates similar to the West, a number report very high prevalence rates.

Guayami Indians from Panama[5] were found to have a prevalence of 57 per 1000, the accompanying case-control study identifying family history (odds ratio 13.9) and febrile convulsions (odds ratio 5.6) as aetiologically important. In Liberia,[6] a prevalence of 28 per 1000 was found that was historically recent and possibly associated with encephalitis. Rwiza et al.[7] in Tanzania villages found prevalence rates between 5.1 and 37.1 per 1000, the use of the same case-finding method on each site suggesting this disparity was not a

Table 1 Description of seizure status of subjects

	Age 16 years or less frequency (%)	Age over 16 years frequency (%)	Total (%)
Active epilepsy, not in remission	15 (35)	9 (21)	24 (56)
Epilepsy in remission on medication	5 (12)	5 (12)	10 (24)
Epilepsy in remission without medication	2 (5)	3 (6)	5 (11)
Single seizure	2 (5)	1 (2)	3 (7)
Provoked seizure	0 (0)	1 (2)	1 (2)
	24 (57)	19 (43)	43 (100)

methodological artefact. Gracia-Noval et al.[8] in Guatamala found a combined prevalence of active and inactive epilepsy of 29 per 1000, attributable to neurocysticercosis. High prevalence rates have also been found in children in Pakistan[9] and India[10] where perinatal adversity and malnutrition were aetiologically implicated. The present study adds to the evidence that areas of unusually high prevalence are found in developing countries, unlike the wealthier countries of the West.

Though the reason for these high prevalence rates has rarely been examined, the assumption that environmental factors are responsible, particularly infective and perinatal, has prevailed. This appears reasonable in view of high transmission rates of neurotropic infections and unfavourable obstetric conditions. Malnutrition[11] and trauma[12] have also been implicated.

The present study used sampling and case-detection methods well-established in the developing world, though reliance on the WHO epilepsy questions may have under-ascertained cases of partial epilepsy during screening, implying that the overall prevalence of epilepsy may have been higher still. The care taken in translation reduced the risk that the high prevalence was an artefact resulting from misunderstanding of the questions though it has to be acknowledged that dependence on descriptions of seizures in vernacular language will inevitably result in uncertainty of diagnosis in some cases, just as it does in developed countries. Though the sample was small, it was representative and because it consisted of a majority of the population, the prevalence estimate is likely to be epidemiologically robust.

Though a strong family history can be caused by a shared environment as well as shared genes, the latter explanation for the high prevalence in the present study is supported by the finding that nearly all the cases had clinical characteristics of primary generalised epilepsy, as well as an onset in late childhood or adolescence and a tendency for the seizure disorder to remit as evidenced by the rates of non-active epilepsy. The high prevalence of epilepsy could have arisen if a proportion of the individuals who originally founded the Zay Society three centuries ago had epilepsy, the community subsequently growing in genetic and geographical isolation. Service development is needed to improve the care of epilepsy in this community and further research is now needed to test the hypothesis that the epilepsy is inherited and to identify the gene responsible.

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